## Consumer Task Force Michigan Quality Community Care Council October 28, 2008 10:00 am - noon

## **MINUTES**

**ATTENDEES**: Roanne Chaney, Jacqui Day, Jill Gerrie, Orystine Gully Laura Hall, Sharon Hall, Sara Harrison, Sharon Hold, Cathy McRae, Marion Owen, Susan Steinke, Cyndy Viars, Colleen Widders, Tammy Yeomans, Jane Alexander, Nora Barkey, Tandy Bidinger, John Jokish, Wendi Middleton, Tari Muñiz, Jackie Tichnell, Drew Walker

**APPROVAL OF THE MINUTES** - Minutes were approved.

**SCHEDULE OF TASK FORCE MEETINGS** - It was agreed to hold the Consumer Task Force meetings every other month, beginning with December 2008. Jackie will send a new schedule of meetings.

**EXECUTIVE COMMITTEE** - These meetings need to restart with minutes back to the entire Task Force.

**SUSTAINABILITY GRANT** - This is the draft "ask" letter that Wendi and Drew are working on for possible continuation funds for the Task Force once the grants end.

- There are funds for 2009 and 2010 in three big grants including Medicaid Infrastructure Grant
- The members see themselves as a bridge between the aging community and the disability community
- It was noted AND stressed that grant funds CANNOT be used for lobbying. There is a difference between advocacy and lobbying. Member may lobby on their own (not representing the Consumer Task Force) or for their employers, but not as a Consumer Task Force representative.
- The "ask" letter from Drew is only a DRAFT that describes the Consumer Task Force. It is not promoting anything at this point
- MDRC was used as a placeholder agency in the draft letter. Other agencies could be asked to submit the "ask" letter for the Consumer Task Force
- If the Consumer Task Force is going after other sources of funding, it is imperative that all sources of funding and activities are kept separate.
- It was noted that the new OSA continuation grant for nursing home diversion was cut by CMS and does not include any funding for the Consumer Task Force.
- The Disability Networks need to reach out to the aging population. Separate grants have separate administrative agencies so it may be hard to coordinate aging with the disability community

- The LTC Supports and Services Advisory Commission has several workgroups, including one on consumer advocacy and participation. These groups do need more consumer representation and input.
- Some members are looking at the Consumer Task Force as a media opportunity. Members could do video presentations to the legislature. Again, this would have to be done on an individual basis, not as a Consumer Task Force representative. Collect video clips, interviews, etc "through our eyes." Provide strong input for change. Use U-Tube or Flicker web sites
- This is a bad time to ask foundations for money. They lost a lot in the stock market.
- MDRC noted they have 2 sources of funding James Bohr foundation and Cookie Gant funds. These are private funds that can be used for consumer advocacy.

**CREATE A MISSION STATEMENT** - At this point, the Consumer Task Force does not have a mission statement. Reference was made back to the contents of the "ask" letter for input. Brainstorming on this subject followed:

- It appears from the "ask" letter that the Consumer Task Force has the same charge as the governor-appointed Commission
- The original grant that created the Consumer Task Force did not detail what the Task Force would do.
- Some of the Consumer Task Force activities include:
  - o education
  - o information sharing
  - o education
  - o attending conferences
  - o reviewing grants prior to submission
  - o provide tangible input and recruitment
- The Task Force needs to stay in touch with the Commission and not duplicate those efforts. Use the public comment portion of the agenda for input
- There is a need to develop a list of values, target audience, core services, unique attributes. Send these to Jackie. She will compile for the next meeting.
- Find another word besides "consumer." Define "consumer" mental health, aging, caregiver, user of services, physically or developmentally disabled, anyone using LTC services
- Consumer access to information is not provided anywhere but the Consumer Task Force
- The Task Force is used as a state funding match for the grants
- There are not many people with disabilities on the Olmstead Coalition

- Consumer Task Force is encouraged to provide input to the Office when they don't agree on things the Office is doing
- This is a consumer-led group
- The Consumer Task Force is more apt to obtain information on the ground floor, where the Commission does not.
- The Consumer Task Force finds gaps and holes in services and policies

**CROSS CULTURE/DIVERSITY WITHIN THE TASK FORCE** - The Office uses the Consumer Task Force in many of its grants. Sometimes, the diversity of the group is requested. Discussion followed:

- Defined as race, ethnics, disabilities, gender, sexual orientation, economics, class, geography, mental health
- Just because a person is of one race, does not mean they can adequately represent that culture.
- Person-centered planning should not care about diversity. We are individuals, regardless of culture, ethnicity, etc.
- The Task Force needs to be aware of its own cultural biases. For example, the drive for independence is not necessarily what a culture may want.
- Geographically, the Task Force needs more attending presentation from the East and North.
- Need to consider a person's ability to attend the meetings. For example, someone from Detroit may have to get up at 4am in order to get ready and drive to Lansing. Phone attendance is always available.
- It was suggested that members poll non-attending members to see if they want to continue to be a participant on the Task Force.
- MDRC pays for transportation to the meetings.

**SYSTEM CHANGE IDEAS** - This item will remain on the agenda. It gives a format for consumers to provide input on ANY systems changes they may want the Office to consider.

- Change the term "consumer"
- Housing and LTC is always an issue
- Prisoners
  - o The state can find added funding for this project and yet not fund other initiatives that have been identified.
  - o 50,000 are in the prison system. A large percent will need LTC, mainly funded by Medicaid.
  - o The state portion of this project should come from Corrections
  - o Will the waiver become a dumping ground
  - o Corrections already has a similar project on a smaller scale
  - The savings should go back into LTC

- Focus on nursing facility transitions of released prisoners already in nursing homes. Detroit has nursing homes that are all released prisoners
- o Corrections has its own definition of medically fragile
- o Get in on the ground floor to shape policy, not react to it
- Foreclosures have people ending up in nursing homes
- The people on SSI cannot afford to rent, they end up in assisted living.
- It's easier to find housing if use assisted living, not really the consumer's choice
- Difficult to find housing for persons with mental health issues. Many assisted living facilities are for persons with mental health issues. A "normal" consumer could end up in a facility with all persons with mental health issues.
- TBI beds have to be in assisted living facility. It is not seen as being able to be in one's own home.
- Housing lack of affordable, accessible housing
- Lack of Section 8 vouchers. End up on wait list.
- High qualifications on other programs such as energy assistance.
- You can spenddown in a nursing home but not in the waiver
- May meet the eligibility requirements for home help, but not be nursing home level of care. It was noted that the Deficit Reduction Act allows for home help eligibility up to 300% SSI. It is possible to use this limit only for home help services, not all Medicaid services. Many of the home help consumers are on Medicare anyway for primary services.
- Maybe make the nursing home a higher level of care than the waiver.
- Make home help a tiered system depending on severity of need
- Maybe have Chris Chesney, chair of the LTC Commission workgroup on finance, listen at the next meeting for the Task Force's concerns with home help and spenddown
- Eligibility and/or availability for services is impacted when the consumer moves to another county. No statewide consistency.
- There is over-screening of people in nursing home. Anecdote: Mental health dumps people in nursing homes or MIChoice if they have a physical issue.
- Timely access to durable medical equipment and assistive technology are barriers to nursing facility transition.
- Buy up foreclosed houses for affordable, accessible housing.

## **OTHER**

o Jackie will send out the notice of the next Commission meeting. They are the 4<sup>th</sup> Monday of the month.